

# **Learning Disabilities Mortality Review (LeDeR)**

**Annual Report Jan – Dec 2019**

**Learning from deaths of people  
with a learning disability**



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## Preface

*“When my daughter died there wasn’t a review process. If there had been it would have given us the confidence that learning would be captured and could prevent other people with learning disabilities dying in similar circumstances”*

**Pam – mother**

*“Its really important to talk to families as they know the person best. You get a real sense of the person and what their life was about”*

**Kate – mother and grandmother**

*“When my son died I wanted someone to come to me and explain what happened and whether something could have been done differently”*

**MaryAnne – mother**

*“At first I though it was a tick box exercise, but the depth of information asked for was surprising and I was very re-assured by the process”*

**Marjorie – sister**

*“Sarah wasn’t just a name, she is a person with people who loved her and we wanted the very best for her. Nobody will learn if you don’t have these reviews”*

**Graham and Mandy – Brother and Sister-in-Law**



# Executive Summary

## Introduction

The LeDeR Programme (Learning from Deaths Review of people with a learning disability) is led by the University of Bristol and follows on from the Confidential Enquiry into the premature deaths of people with Learning Disability (CIPOLD) 2013. The findings of this report demonstrated that on average someone with a learning disability lives 20 years less than the general population.

The issues and causes of death identified within the national LeDeR annual report (published May 2019) reflect the many challenges that people with a learning disability face. There is much work already underway locally to improve access to healthcare and to address health inequality for people with a learning disability. Through the development of new tools to support practitioners, new resources to develop skills and awareness, and strengthened LeDeR processes, we aim to create a stronger culture of person-centred care to improve access, with vigilant and proactive support for people with a learning disability. We recognise we are on the beginning of this journey and there is more for us to do to ensure all people using health and social care have an equitable service.

We have a strong commitment to learn from these reviews and Chapters 7 and 8 set out the recommendations from reviewers and our dedication to turn this into real action promoting learning throughout health and social care services.

In February 2019, we established the BNSSG LeDeR Steering Group. Working closely with our system partners, we have discussed how to direct and progress our plans to implement the LeDeR programme across the CCG area and ensure we have a robust process for reviewing and learning from the deaths of people with a learning disability.

This is the first annual report on the deaths of people with learning disabilities who lived in the Bristol, North Somerset and South Gloucestershire area. The purpose of the report is to share our findings from LeDeR reviews and to identify learning and changes for practice.

A positive development from our work at the end of this year has been to establish a LeDeR Service User Forum in partnership with North Somerset People First who are helping us understand people learning disabilities' day to day experiences of accessing health care. Their insights and expertise is invaluable to helping us look at service delivery from a different perspective and keeps us practically focussed on what will make a difference.

Going forward we are passionately committed to listening and learning from these reviews, from people with learning disabilities and their families and making real changes across the health care system. We will challenge health inequality and improve health outcomes for people with learning disabilities and aim to prevent people from dying prematurely.

**Alison Moon**  
**Chair of the BNSSG LeDeR**  
**Steering Group**

**Rosi Shepherd**  
**Executive Director of Nursing**

# Chapter One - Structure for LeDeR

## 1.1 Background

The Learning Disabilities Mortality Review Programme was established in 2015. LeDeR is a non-statutory process set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. All deaths of people with learning disability over the age of 4 years are subject to a Learning Disability Mortality Review.

The main purpose of the LeDeR review is to:

- Identify any potentially avoidable factors that may have contributed to the person's death, and
- Develop plans of action that individually or in combination, will guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities.

Following the roll out of the pilot programme the LeDeR Programme was fully implemented across England by December 2017. All Clinical Commissioning Groups/STP areas were required to establish a LeDeR Steering Group during 2017/18, though this was slightly delayed in BNSSG due to the merger of the three CCGs and was quickly established in the autumn of 2018

The LeDeR programme uses the definition of people with learning disabilities included in 'Valuing People', the 2001 White Paper on the health and social care:

- Significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- Reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development

## 1.2 LeDeR Programme Process

### Overview of the national LeDeR process

The National LeDeR Programme, run by the University of Bristol established a process where by all LD deaths over the age of 4 years are subject to an initial review. These reviews focus on the individual's last year of life and include a pen portrait (*an informal description of a person focusing on 'softer' dimensions, such as attitudes, lifestyle and appearance, to provide a better understanding of the person*), and a review of any medical and social care the person received. Importantly, the review includes making contact with a member of the family or carer, and their involvement in writing the pen portrait is key. The LeDeR guidance states that these are not investigations, but reviews, with the focus on identifying learning and not apportioning blame.



The final element of the LeDeR review process is to complete a scoring grid on the level of care provided. This is based on the outcome of the reviewer's assessment of the individual's care. The scoring is from 1 (excellent) to 6 (fell short of expected practice), and is detailed in table 5 on page 18 of the report.

The reviewer is required to identify areas of best practice and areas where improvements could be made. Where significant concerns have been highlighted then the reviewer may recommend a Multi-Agency Review (MAR) is completed. This part of the LeDeR process requires all the health and social care individuals who were involved in the person's care to come together to discuss the case and agree on recommendations to take forward for improving care. The family is also invited to attend, and again is key to providing the background to the individual.

Following either the initial review or a MAR the case is reviewed by the lead local person for the LeDeR programme, referred to as the Local Area Contact (LAC), to ensure all matters have been covered and learning has been identified. The LAC then completes a Quality Assurance checklist and the case is closed. An anonymised version of the case is generated and shared with all relevant organisations, if the family has given permission. To support early identification of themes for improvements in care, NHSE has recommended that LeDeR reviews are completed within 6 months of notification.

## **Local BNSSG LeDeR Process and Governance**

### **Steering Group**

As part of the LeDeR programme, each STP area is required to establish a Steering Group with the remit to guide the implementation of the LeDeR programme within the area. The Executive lead responsible for the programme is the Director of Nursing. In February 2019, we held our first BNSSG Steering Group and which has met monthly since this date. Representatives attend the Steering Group from all BNSSG health providers, the three BNSSG local authorities which provide adult social care, the Care Quality Commission, GPs and NHS England regional LeDeR leads.

Our Steering Group is chaired by the Independent Registered Nurse member of our Governing Body and reports to the CCG's Quality Committee and through them to the Governing Body. The CCG has responsibility for system leadership of the programme. The Steering Group aims to take a strategic level oversight of the reviews of deaths of people with learning disabilities, driving transformation to improve care. The role of the LeDeR Steering Group is to:

- Guide the implementation of the programme of local reviews of deaths of people with learning disabilities
- Receive regular updates from the Local Area Contact (LAC) about the local reviews of deaths of people with learning disabilities
- Monitor action plans resulting from local reviews of deaths
- Take appropriate action as a result of information obtained from local reviews of deaths
- To support the identification of and sharing of best practice in the review process
- For committee members to provide shared governance for LeDeR and reporting back to their own organisations



Assurance updates are supplied to the Quality Committee via the group's minutes of the meetings and regular governance reports. The Quality Committee provides assurance and update reports to the Governing Body.

To support the LeDeR process within BNSSG we drafted a LeDeR Framework Policy providing clear guidance on the process and governance to support learning from reviewing these cases. The policy was presented to the BNSSG CCG's Governing Body in September where it was approved and is now available on the CCG's website



### **Clinical Case Review Panel**

To strengthen the LeDeR quality assurance process, the BNSSG Steering Group suggested the addition of a Clinical Case Review Panel to the process. It is important to us that we have assurance for the consistency of the grading and the quality of the reviews. The panel was established in July 2019 and membership includes the Local Area Contact, Clinical Lead GP for Mental Health and Learning Disabilities, CCG safeguarding representative, social care representative and LeDeR co-ordinator. We are the only CCG in the country that has this additional element to the national process. This panel was agreed by both national and regional LeDeR leads, supporting our approach to enhancing the quality assurance process. The panel review all completed cases to ensure all questions have been fully answered, learning and any best practice identified, and appropriate recommendations formulated prior to closing the case on the LeDeR platform.

### **Key individuals**

To lead and manage the LeDeR process within BNSSG there are key individuals who have this responsibility. We have two Local Area Contacts (LAC) who act as the supervisor of the local process, a LeDeR co-ordinator and a LeDeR administrator to support the LeDeR review process. The Local Area Contact's oversee the allocation of cases to trained LeDeR reviewers, monitor the progress and completion of reviews and provide quality assurance in the closure process of each case. The LeDeR process is supported by a team of trained reviewers from local health and social care organisations in BNSSG.

Since role out across BNSSG of the programme in 2017 we have trained a total of 29 reviewers. The majority of reviewers are volunteers who undertake reviews in addition to their day job, the majority are nurses or allied health professionals. For a number of reasons, including change in role and circumstances, not all of these reviewers remain active. At the end of 2019 we had 11 active reviewers. Securing sufficient numbers of appropriate, trained and experienced reviewers is a challenge for BNSSG and we are considering new approaches for 2020/21.

## Buddy Reviewer system for first LeDeR Review

To support the reviewers with their first few reviews we set up a 'Buddy System' during 2019. Buddies are reviewers with experience of completing a number of LeDeR reviews and have a wealth of knowledge on the process. The buddies act as a point of contact for advice on where to start, how to approach providers and or families and how to complete a quality review.

## Peer Support Meetings

In addition to the Buddy System, during 2019 we established Peer Support Meetings to offer additional support to our LeDeR reviewers. Meetings are held on a bi-monthly basis and although they follow an agenda these meetings are less formal than the Steering Group and Clinical Case Review Panel. The meetings are the reviewer's opportunity to tell the Local Area Contact and the administrator of any issues or blocks they may be facing and share their experiences and ideas with other local reviewers.

These meetings also give the LAC and administrator a chance to update reviewers on information from the Steering Group and other events since the last meeting. Reviewers are also able to update them on anything they are aware of or need, such as training and support needs.

These meetings although not compulsory do benefit many reviewers, whether this is through having a safe space to raise any concerns or speaking to other reviewers as to how they might approach a situation. During 2019 we held 3 meetings and have rotated these around the BNSSG area to encourage good attendance from all our reviewers.

## LeDeR Service User Forum

We want people with learning disabilities to have the opportunity to contribute in the LeDeR review process and ensure people are fully supported to participate equally, feeding their comments and ideas on the findings of the reviews to the LeDeR Steering Group. We are developing a LeDeR Service User Forum in partnership with North Somerset People First, comprising of up to 16 members with learning disabilities to meet quarterly. The LeDeR Service User Forum voices began contributing fully to the Steering Group in February 2020.





## Governance and Assurance

In the setting up of the BNSSG LeDeR systems a Governance Action Plan was drafted to support and monitor full implementation of the LeDeR programme. The majority of the initial actions have now been closed, but updates and any new programme actions are reviewed monthly at Steering Group meetings.

To provide further assurance of our approach and management of the LeDeR process an independent review was commissioned in July 2019. The review highlighted an overall compliance with the national process, noting good practice in the quality of reviews, the implementation of the Peer Review Group and Buddy System, overall compliance in duties by the Local Area Contacts and implementation of the Clinical Case Review Panel for the closure of cases. The independent review also made recommendations to further strengthen current arrangements and these were added to the Governance Action Plan to ensure they were addressed. The action plan is monitored by the Steering Group and assurance provided to the Quality Committee.

## Chapter Two - Deaths notified to the LeDeR programme

### 2.1 Notifications

Since the programme began in 2017 there have been **102** deaths reported to the BNSSG LeDeR platform covering the period July 2017 to end of December 2019, with 43 reviews in total completed to the end of 2019. Following the initial pilot of the programme, NHSE estimated that for the BNSSG area we would expect to review approximately 57 deaths of people with a learning disability each year. At the start of the programme, advice and guidance was circulated to all health and social care providers and GP practices, though notifications for 2017 (3) and 2018 (43) were lower than expected. Throughout 2019 regular reminders have been sent out on how to complete notifications. This had a positive impact and at the end of 2019 there were **56** cases reported.

The table below provides a summary of the status of all cases as at 31<sup>st</sup> December 2019.

**Table 1: Summary of deaths notified in 2019**

<b>Total notifications in 2019</b>	<b>56</b>
Total notifications not yet assigned to a reviewer	19
Total number of reviews currently in progress (inc previous years)	41
Number of multi-agency reviews (MARS) undertaken in 2019	1
<b>Completed reviews in 2019</b>	<b>32</b>
Closed reviews to date (since 2017)	43

There were three cases referred for a Multi-Agency Review (MAR), of which one was held in December 2019. Two further cases will take place in 2020. A total of 32 cases were completed in the year, with the majority of these relating to 2018 cases.

The table below shows the number reported and the numbers of these cases now closed for that year.

**Table 2 – Status of reviews by year**

<b>Year</b>	<b>Closed</b>	<b>Open</b>	<b>Total</b>	<b>% completed</b>
2017 (January to December)	3	0	3	100%
2018 (January to December)	33	12	45	76%
2019 (January to December)	32	26	58	17%
<b>Total</b>	<b>68</b>	<b>38</b>	<b>106</b>	<b>37%</b>

NHSE key performance indicators for LeDeR activity require all reviews to be allocated to a reviewer within 3 months of notification, for reviews to be completed within 6 months of notification and the quality assurance of reviews by the LAC within 2 weeks of completion.

**Table 3: During 2019 our LeDeR performance:**

Allocation of reviewers within 3 months of notification	26%	This KPI was not met due to a shortage of LeDeR reviewers – see below
Completion of reviews within 6 months of notification	7%	This KPI was not met due to the delay in allocating cases to reviewers.
Quality Assurance of reviews by the LAC within 2 weeks of completion.	100%	This KPI was met. All cases are initially reviewed by LAC within two weeks of completion & added to the next Clinical Case Review Panel for quality review prior to closure.

The majority of our LeDeR reviewers are volunteers who undertake reviews in addition to their day job, many of them are clinical professionals working in hospitals or in the community so they often have limited time to dedicate to complete reviews. We are grateful for their time and commitment to contribute to improving health care for people with learning disabilities.

### **Actions taken to address KPI's**

In November we developed a recruitment pack to encourage more people to become reviewers and this has had an impact in the later part of 2019 increasing the numbers of reviewers, which allowed us to allocate cases more quickly.

We have also implemented weekly follow-up with reviewers to ask how their cases are progressing, checking if they need any support from us to access notes or querying if there is anything that is delaying them from completing the review.

We also held weekly Clinical Review Panels throughout March and this has had a real impact on improving completion rates in the first quarter of 2020 from 37% at 31<sup>st</sup> December to 53% at 31<sup>st</sup> March 2020.

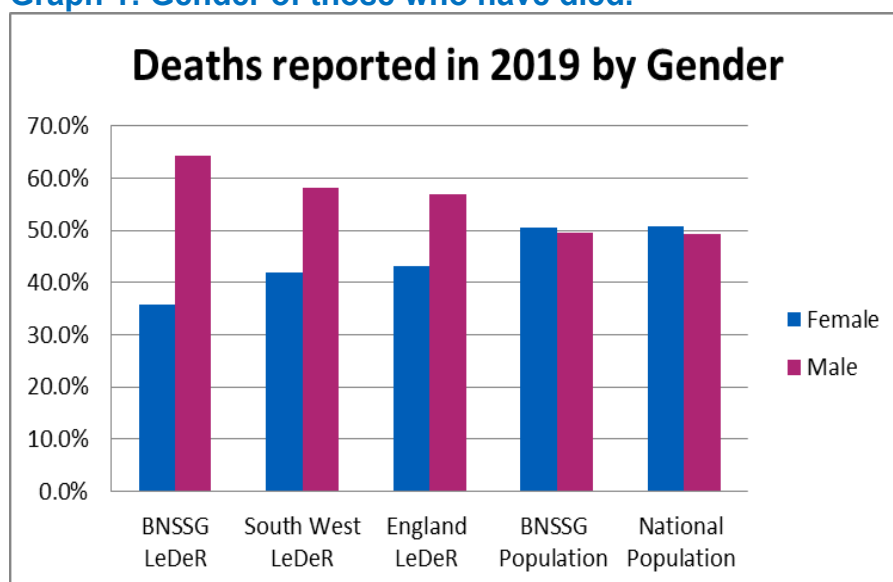
<b>Regional Clinical Commissioning Group Figures as at 31<sup>st</sup> December 2019</b>							
	Total notified	Unallocated	In Progress	Completed	Unallocated %	In progress %	Completed %
<b>SOUTH WEST</b>	<b>688</b>	<b>147</b>	<b>262</b>	<b>279</b>	<b>21%</b>	<b>38%</b>	<b>41%</b>
BANES, Wiltshire and Swindon	82	33	26	23	40%	32%	28%
NHS BATH AND NORTH EAST SOMERSET CCG	18	5	7	6	28%	39%	33%
NHS SWINDON CCG	17	8	2	7	47%	12%	41%
NHS WILTSHIRE CCG	47	20	17	10	43%	36%	21%
NHS BRISTOL, NORTH SOMERSET & SOUTH GLOUCESTERSHIRE CCG	106	21	46	39	20%	43%	37%
NHS KERNOW CCG	66	30	23	13	45%	35%	20%
NHS DEVON CCG	115	32	60	23	28%	52%	20%
NHS DORSET CCG	116	16	46	54	14%	40%	47%
NHS GLOUCESTERSHIRE CCG	132	15	29	88	11%	22%	67%
NHS SOMERSET CCG	71	0	32	39	0%	45%	55%

## Chapter Three - About people who died

### 3.1 Demographic data

The following graphs provide details of the demographic of the individuals who died. Graph 1 shows the gender of those who died. This demonstrates that 64% of deaths reported were males, this compares to 58% for the South West and 57% in England. The graph also shows comparisons with the full BNSSG (50%) and England (49%) population percentages.

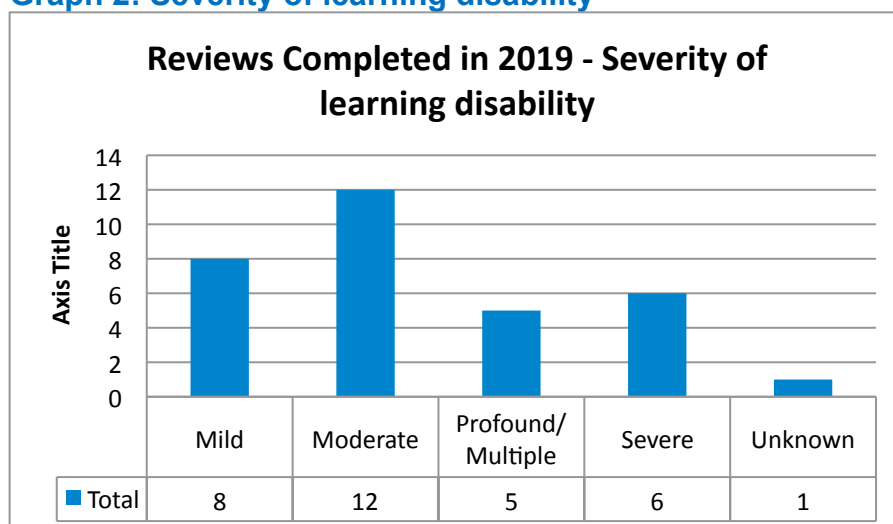
**Graph 1: Gender of those who have died.**



The percentage difference of male to female deaths is more marked in BNSSG when compared to the South West and England, however, this may be due to the low numbers of deaths so will be something that is explored further as the pool of data increases over the coming years.

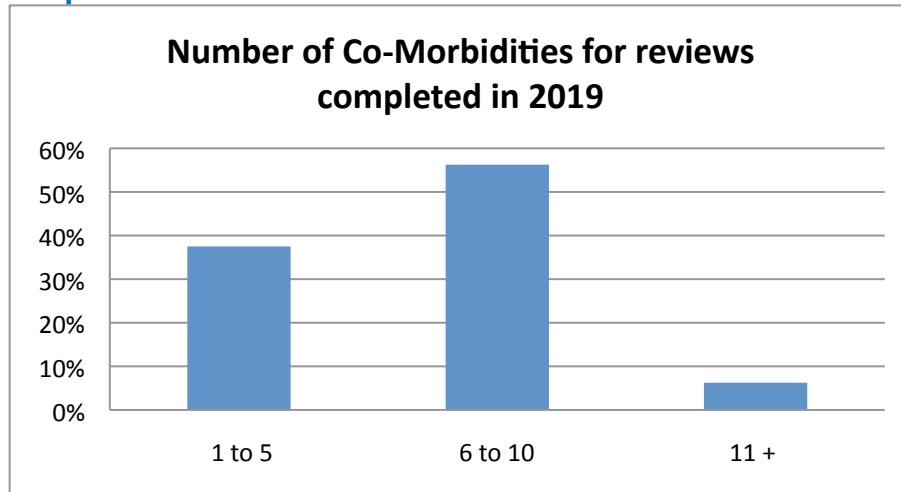
When we compared the ethnicity of those who died, all but one was stated as 'White-British'. This will be discussed and guidance provided to reviewers on checking ethnicity as part of their discussion with families and carers.

**Graph 2: Severity of learning disability**



The data in graph 2 relates to the 32 completed reviews only in 2019. As numbers are small it can be seen that there has been a range of levels of severity and the highest number is for moderate learning disability.

**Graph 3: Number of co-morbidities**



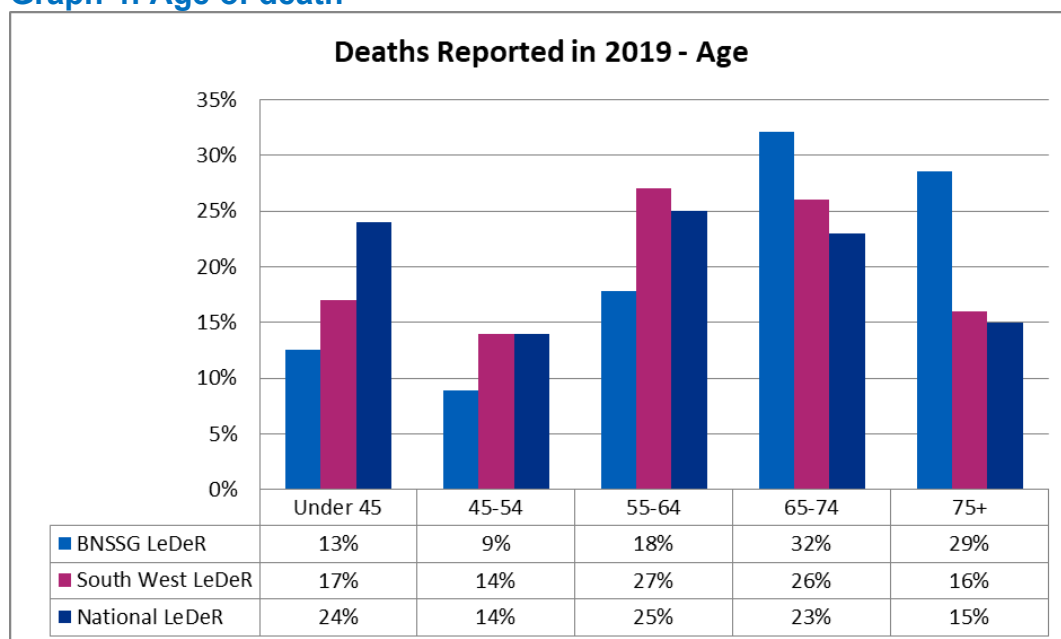
The highest number of co-morbidities for one individual was 15. There were no individuals identified who had no other co-existing illnesses.

## Chapter Four - Statistics

### 4.1 Notification Data and Review Findings

The first three graphs are based on the 56 notifications received in 2019. Within the initial notification the individual's age, date of death and place of death are recorded. All subsequent details can only be obtained following completion of the reviews.

**Graph 4: Age of death**



Graph 4 shows the age of the individual grouped in age ranges and compared with South West and National LeDeR data. It can be seen that within BNSSG people with a learning disability on average live longer than in other parts of the South West and England. In the table below the median age is given demonstrating this further.

**Table 4: Median Age of death**

	BNSSG LeDeR		BNSSG LeDeR Overall	South West LeDeR	National LeDeR
	Female	Male			
2019	65.5	71.5	68	62	60

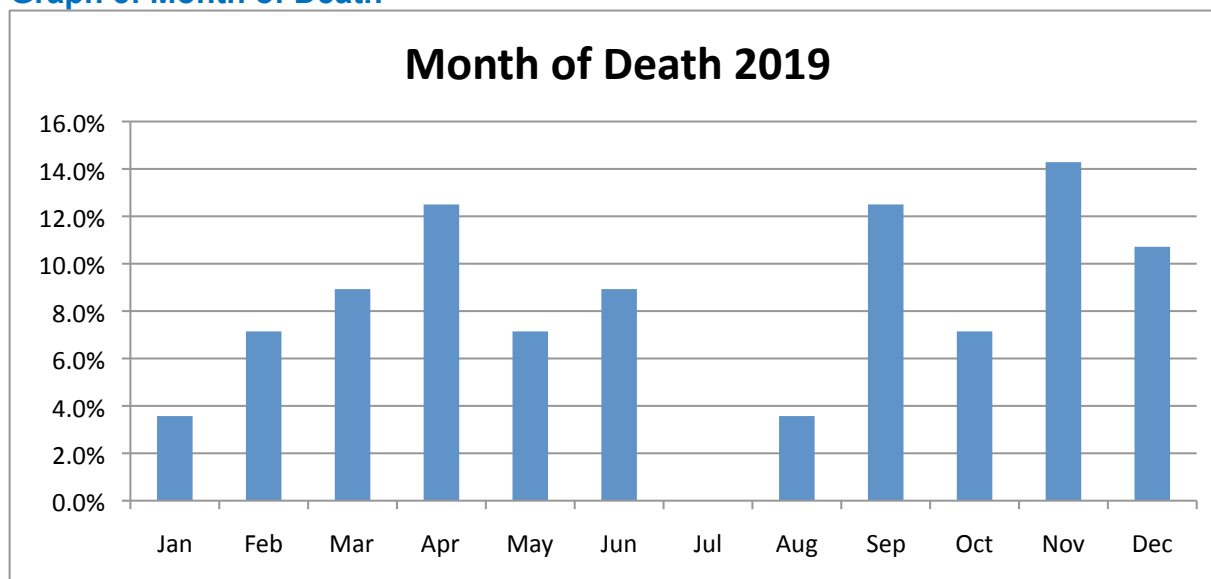
Reviewing the national data it is noted that males with a learning disability live slightly longer than women (by 1 year only); however this difference is more noticeable within the BNSSG data. This may be due to the small number of cases that have been analysed but will be explored further in 2020 as the pool of data increases.

Graph 5 below shows deaths by month. At this stage we are unable to state if any specific seasonal variations have an impact on this data.

During 2019, we sent out reminders to all providers and there has been an increased level of reporting month on month of deaths people with a learning disability. The Local LeDeR team discuss reporting with providers on a monthly basis and link this with sharing learning identified from LeDeR reviews.

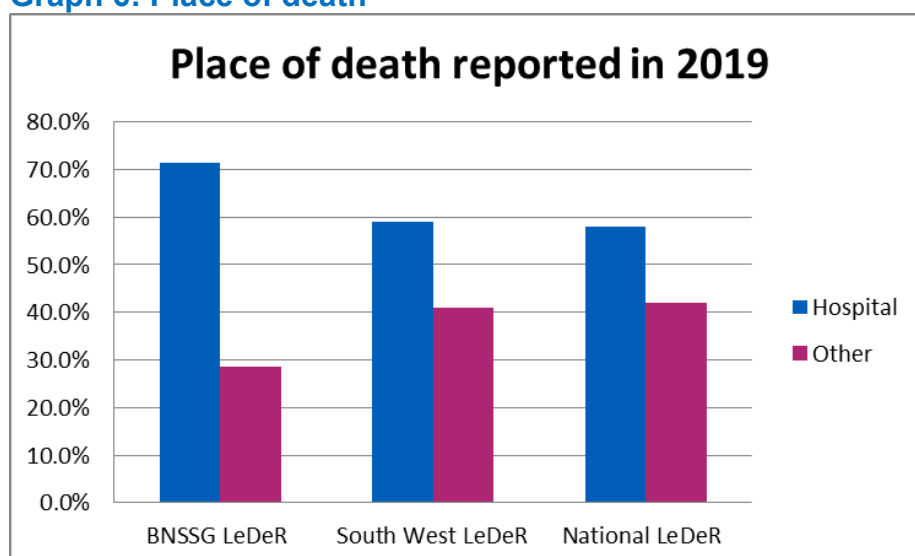


**Graph 5: Month of Death**



Graph 6 shows the place of death for cases reported in 2019. For BNSSG over 70% of the deaths occurred in hospital compared to 59% in the South West and 57% in England. It is difficult to explain why this may be the case, but the acute trusts within BNSSG have incorporated the notification of deaths of people with learning disabilities into their mortality processes, so there is a hypothesis that these may be more robust than other trusts within the region and country, or alternatively, the out of hospital deaths are not all reported within BNSSG. In 2020 we will focus further on ensuring primary care, community health and social care providers are aware of the LeDeR programme and we will support them to report all deaths of people with a learning disability.

**Graph 6: Place of death**

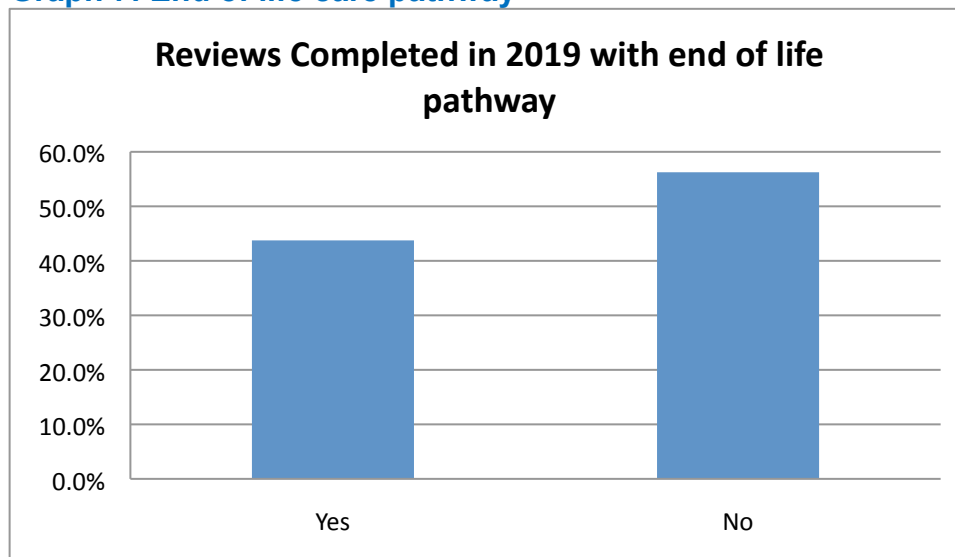


Whether an individual's choice for their place of death was taken into account is not currently recorded through the review process. This has been highlighted to the national team for consideration and potential inclusion when reviewing the programme in 2020.

## The following data is based on the 32 completed cases during 2019

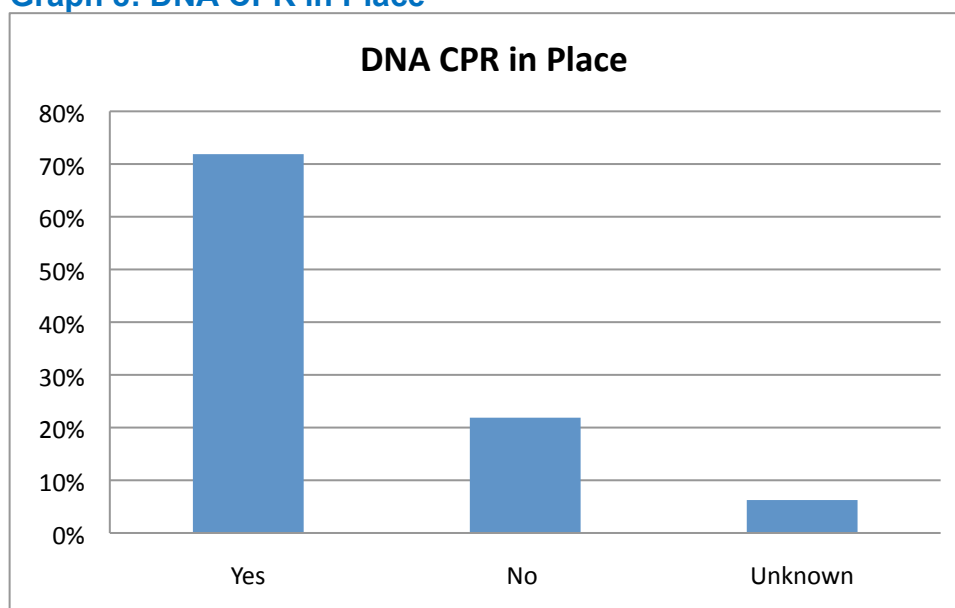
Within the review there is a requirement to understand if end of life care planning was in place for those where death was expected. The following graph shows that this was the case for just over 40% of the reviews.

**Graph 7: End of life care pathway**

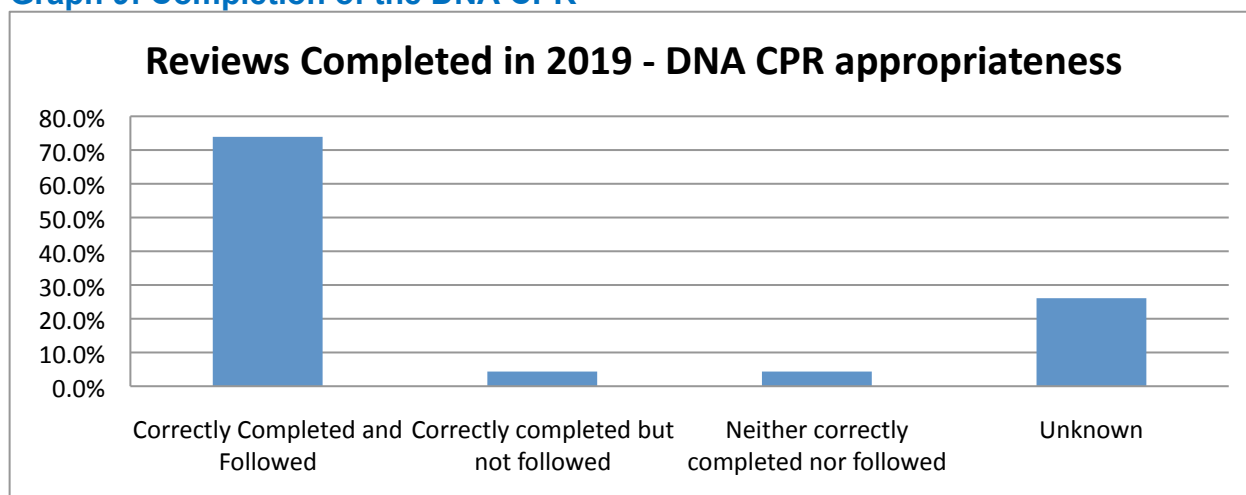


In addition, the reviews look to see if a Do Not Attempt Cardio-Pulmonary Resuscitation order was in place or not. The following graph 8 provides this data showing that for 72% of the reviews this was the case. The following graph (graph 9) provides information on whether this was appropriately completed and carried out.

**Graph 8: DNA CPR in Place**



**Graph 9: Completion of the DNA CPR**



Of the reviews where a DNA CPR order was in place the reviewers noted that 74% were correctly completed and followed. Due to the limitations of the review process it is not always possible for the reviewer to assess appropriateness due to a lack of available documentation. We will work with our providers to ensure that documentation is fully available for reviews.

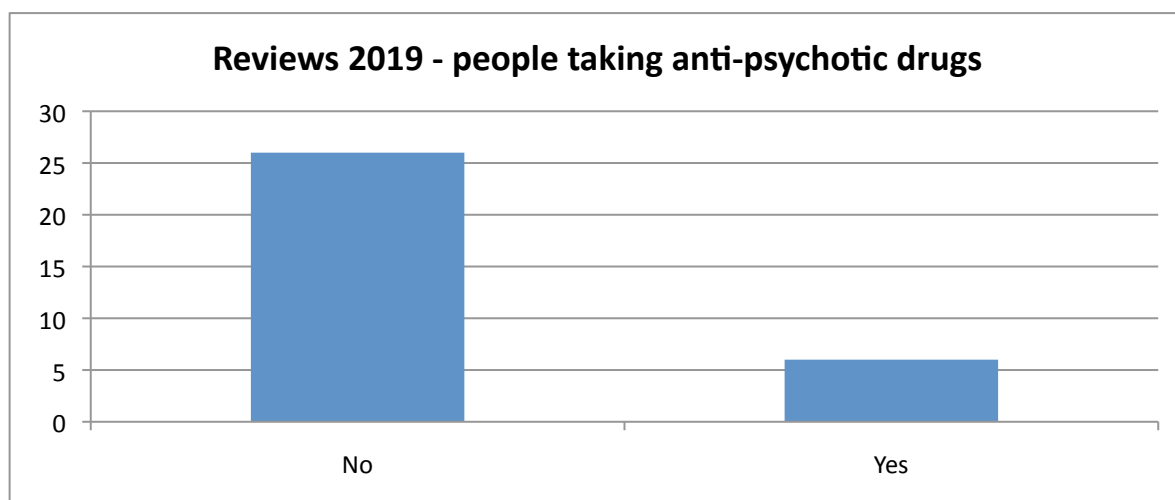
The reviewer is also required to record the cause of death as detailed on the death certificate. From the completed reviews, 47% of deaths were related to pneumonia as the primary cause, as shown below:

Type of pneumonia	Percentage of the 47%
Generic Pneumonia	47%
Bronchial Pneumonia	13%
Aspiration Pneumonia	40%

The next most frequently reported cause of death was Sepsis (16%). Dementia (9%) and cancer (9%) were the next most commonly occurring causes of death.

Reviews have identified that a small number of death certificates state, for example, 'learning disability' or 'Down's Syndrome' as a secondary cause of death. It is incorrect to state this. The LeDeR team will discuss this with the Coroner's Office to ensure appropriate guidance is given to clinicians. We will also raise this issue with providers to address in learning disability awareness training for medical staff.

**Graph 10: People taking anti-psychotic drugs**

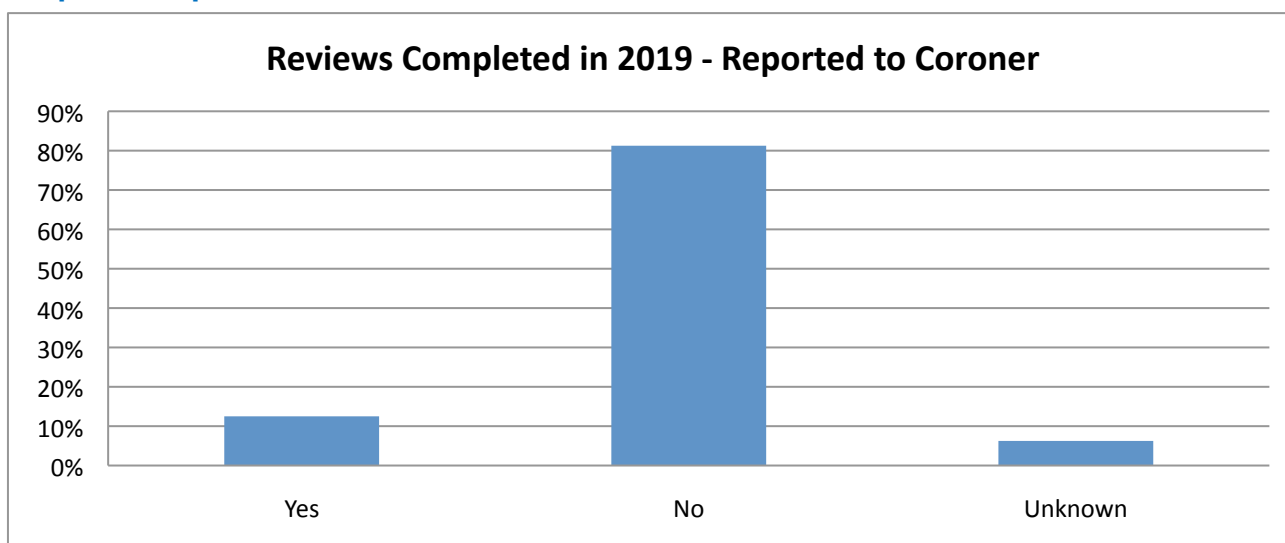


The completed cases include a review of the individual's medication, when they last had a medical review of medications, and specifically if they were prescribed an antipsychotic. From graph 10 it is evident that the majority of individuals were not prescribed antipsychotic medication.

In addition to understanding the individual's past medical history the reviewers also explore if they were receiving any specialist services. In the completed cases, 100% had received some degree of specialist services input.

It was also noted that 12% of the cases were reported to the coroner, with 81% not and 7% unknown.

**Graph 11: reported to the Coroner**



## Chapter Five - Quality of Care Provided

### 5.1 Indicators of the quality of care provided

As stated previously, the aim of undertaking LeDeR reviews is to share learning from when care has gone well to support people with Learning Disabilities live full and enriching lives. The aim is also to identify learning from when things haven't gone as well for an individual and to use this information to support improvements in the health and social care for others. It is important to us that the assurance for the consistency of the grading and the quality of each review is discussed at the Clinical Case Review Panel. We are the only CCG in the country that has this additional quality assurance process.

### 5.2 Assessment of the quality of care

On completion of a case the reviewer is required to make an assessment of the level of care provided on a range from 1 (excellent) to 6 (Care fell far short of expectations). The following table shows the level of care provided for the 32 completed reviews in 2019. 9 out of 10 people with a learning disability in BNSSG received care that is satisfactory or better, and there were no cases where it was identified that the care received contributed to the death of the individual in 2019.

**Table 5: Grading of care**

Care Score	Percentages	Total & Ratio
1 - This was excellent care and met current best practice.	0%	29/32 9:10
2 - This was good care	72%	
3 - This was satisfactory care	19%	
4 - Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death.	6%	3/32 1:10
5 - Care fell short of current best practice in one or more significant areas, although this is not considered to have had the potential for adverse impact on the person, some learning could result from a fuller review of the death.	3%	
6 - Care fell far short of expected good practice and this contributed to the cause of death.	0%	

The Clinical Case Review Panel noted areas of good practice including:

- Regular staff continuing to visit the person whilst they were in hospital or hospice.
- GP undertaking home visits to support the person staying at home.
- Best interest decision-making meetings involving family.
- Multi-disciplinary meetings to review full care of the person, including physical health needs and cognitive and behavioural needs.

### Examples of best practice;

- People with learning disabilities and/or autism in hospital having a clear easy read hospital passport
- Having a designated person responsible for coordinating the person's healthcare needs

### 5.3 Delays in the person's care or treatment that adversely affected their health

The panel looks specifically for any delays in a person's care or treatment, which had a negative impact. In reviewing the 32 cases completed in 2019 there were three where the case reviewer and the Panel were concerned about the impact of delays and therefore recommended a further multi-agency review of the case. One MAR was held in 2019 and this case is detailed in the MAR section below.

### 5.4 Problems with organisational systems and processes that led to a poor standard of care

The Panel also looks to see if the organisations involved in an individual's care have ensured that the individual's needs have been addressed appropriately, reasonable adjustments made, and that they have communicated well with other providers to ensure the safe and effective transfer of care.

The reviews highlighted some reasonable adjustments providers had made, such as:

- numbing cream & distraction techniques for people with needle phobias
- booking people at the end of a clinic to give them more time
- providing some information in Easy Read
- preparation visits to hospitals and clinics to build people's confidence



However the reviews have also shown that the communication between providers could be better and that there are cases where this has led to delays and misunderstanding about what is needed for an individual. Likewise services sometimes have a poor understanding of reasonable adjustments, and more work needs to be done to address this

### 5.5 Service provision gaps that may have contributed to the person's death

As stated above, from the 32 completed reviews, there were only three cases where the panel felt more information was needed to allow a full review of an individual's care. One of these cases has progressed to a MAR held in December 2019 and the other two are planned for early 2020. Highlighted issues related to communication of diagnosis and palliative care arrangements. Findings from the case that was discussed at the MAR meeting are given below.



## 5.6 Any concerns about the death

The Clinical Case Review Panel also has a responsibility to identify if there were any concerns about an individual's care that led the panel to have concerns about the individual dying when they did. No concerns were identified for cases this year

## 5.7 The findings of multi-agency review panels

During 2019 one MAR was held in December 2019. The main areas of concern for this case related to communications with the family, communications between providers of care, and awareness and acknowledgement of behaviour changes which may be an indication of ill health.

The recommendations from this case have been presented below. From these an action plan will be drafted and compliance will be monitored at the Steering Group.

- |  |
|--|
| <ul style="list-style-type: none"><li>• Care home staff should keep families informed about health concerns and hospital appointments for their next of kin and involve them in appointments where important results or decisions may be shared so they can support and advocate for their relative and be prepared for the changes</li></ul>  |
| <ul style="list-style-type: none"><li>• When GPs are treating people with a learning disability who are unwell particularly when there are a number of apparently unrelated symptoms, they should consider all of the recent signs and symptoms together and also consider whether they have all the information they need to plan treatment for the person</li></ul>                                |
| <ul style="list-style-type: none"><li>• When someone with a learning disability is diagnosed with a life limiting condition /prognosis There should be early consideration of involvement of the district nursing service or hospice care to get to know the person and build trust and support care delivery in the home</li></ul>  |
| <ul style="list-style-type: none"><li>• Hospital doctors should call the GP if malignancy is a high concern for a patient with a learning disability where possible to ensure that actions and information are progressed as soon as possible for care and treatment planning</li></ul>  |
| <ul style="list-style-type: none"><li>• Acute trust staff should remember to communicate directly with families / next of kin for people with a learning disability as well as with the GP and Care Home</li></ul>   |
| <ul style="list-style-type: none"><li>• Training in health care for care staff for people with a learning disability should include the common signs and symptoms of cancer and the importance of reminding the GPs of all of the recent health history for the person including hospital attendances and recent GP appointments to help them advocate on behalf on behalf of their client</li></ul> |

## Chapter Six - Deaths of children

### 6.1 Child death data

During 2019, 3 cases were notified to the LeDeR platform, which related to the death of a child with learning disabilities. All child deaths are reviewed as part of the statutory child death overview process and therefore separate learning disability mortality reviews are not undertaken. During 2019 no case was concluded.

Due to the small number of cases, demographic data has been withheld to prevent inadvertent identification of the individuals.

# Chapter Seven - Recommendations from reviewers

## 7.1 Recommendations made by reviewers for local action

All recommendations from reviews will be developed into an action plan with our partners defining our priorities across the system. The following recommendations for action have been collated from LeDeR Reviews over the last year;

- Every person with learning disability should be invited for an annual health check by their GP supported where required by community providers
- Following an annual health check, each person has a health action plan – CLDT's should check this is in place
- Reasonable adjustments may require innovation & thinking 'outside the box' to support people to access services. This is best done with family or support staff who knows the person really well.
- Providers should identify people with learning disabilities who have repeat admissions for constipation related issues and flag this to GPs in discharge letters
- Constipation was a factor in a large number of cases - people with learning disabilities need support to drink more water every day and eat foods to help address this
- Support people with learning disabilities to have regular check-ups about their medicines
- Reasonable adjustments need to be made for people with learning disabilities for health tests and investigations
- Diagnostic screening staff need training on how to support people with learning disabilities to be screened including how to make reasonable adjustments
- Reasonable adjustments and risk assessments must be in place for all those with dysphagia to ensure they are appropriately supported and supervised with drinking and swallowing especially at mealtimes.
  - People with learning disabilities should be supported to have an annual flu jab.



- Respiratory specialists need to be involved in improving access and treatment for people with learning disabilities with respiratory conditions to prevent people from dying prematurely
- People with learning disabilities who have epilepsy should be reviewed by a Consultant Neurologist and/or a specialist epilepsy nurse for poor seizure control or a medication reduction if the person has been seizure free for several years

## 7.2 Clinical Case Review Panel identified themes

From an overview of completed local reviews during 2019, BNSSG CCG has identified similar themes to those identified in the 2018 national LeDeR report. These focus on areas where improvements can be made to improve the health and social care for this group of people.

The themes have been grouped under six broad headings and will inform the work programme for 2020 for quality improvements.

*NB. there was sometimes more than one theme per review.*

**Table 6: table of learning themes**

Learning theme	Number identified in closed LeDeR reviews
Physical health care*	11
Annual health checks and action plans	10
Reasonable adjustments	7
Legal Frameworks including; Best interest, MCA and DoLs	6
Record keeping and communication	6
End of life care	5

\*The physical health care theme includes improvements in screening, immunisation, detection of sepsis and deterioration, constipation and aspiration pneumonia.

These themes plus the recommendations from a closed case from 2018 were discussed at the December LeDeR Steering Group where it was agreed on the key areas to progress further during 2020.

We are awaiting publication of the Independent Review for this case and we welcome any recommendations made by the review and these will be prioritised in our action plan.

The learning from the closed case included themes relating to specific learning disability and Autism training requirements, mental capacity act and consent training, use of hospital passports and transition arrangements for children to adult services.

The action plan was devised to gain assurance from all providers within BNSSG and was monitored on a monthly basis at the Steering Group. At the end of 2019, the Steering Group agreed the areas to be taken forward as priorities for further transformation quality improvement work or those that would continue as mainstream requirements as part of an organisation's learning disability provision.



The Steering Group will regularly review the agreed themes during the coming year to ensure they are progressed and remain relevant.

In December Healthier Together, the Bristol, North Somerset and South Gloucestershire Strategic Transformation Partnership, established a Learning Disability Programme Board (LDPB). The LDPB has representation from all partner agencies to ensure full system wide engagement to develop and implement a Learning Disabilities and Autism Strategy for BNSSG.

The LeDeR Steering Group will provide regular information on the learning themes and recommendations identified from LeDeR reviews to the Learning Disability Programme Board to inform their programme of work, and some of the agreed priorities will be progressed as part of the Learning Disability Programme Board transformation work.

## Chapter Eight - Conclusion and recommendations

### 8.1 Conclusion

This is the first Learning Disability Mortality Review (LeDeR) annual report for Bristol, North Somerset and South Gloucestershire CCG. The report provides the detail of how the LeDeR process has been implemented, demonstrating the governance arrangements to support a robust approach to learning from the deaths of people with learning disabilities. The BNSSG LeDeR approach has been enhanced by the addition of a Clinical Case Review Panel to support an effective quality assurance closure process.

Our compliance with the NHSE key performance indicators demonstrates the need to have an adequate resource of reviewers to be able to allocate and complete reviews within the given timeframes and this will be strong focus for us in 2020/21.

The data showed we received 56 notifications and completed and closed 32 cases during 2019. In BNSSG our data shows that people with a learning disability live approximately 8 years longer than the national average, and from the completed reviews that 9 out of 10 people with a learning disability received satisfactory or good care.

From the reviews these were areas identified for improvement for care of people with learning disabilities including:

- focusing on communications between professionals,
- improving uptake of the annual health checks,
- early detection access to screening programmes
- management of illnesses, such as pneumonia and sepsis

### 8.2 Recommendations

All recommendations from reviews will be developed into an action plan with our partners from all providers and that will define our priorities across the system for improving the health and social care provided to people with learning disabilities. This action plan will be reviewed and monitored by the LeDeR Steering Group. The action plan will be agreed at the May 2020 Steering Group and published on the CCG LeDeR page.

We are passionately committed to keeping this LeDeR work programme moving forward and we want to strengthen our partnership with North Somerset People First. Their expertise and guidance will help us develop and establish the voice of people with learning disabilities across BNSSG and their experiences will drive our work.

The report also identifies areas where further work is required in 2020. This includes:

- As partners across the system we embed sustained learning and improvement of care for people with learning disabilities. Ensuring learning identified from reviews informs day to day practice in hospitals, community health and social care.
- To develop the whole primary care approach to people with learning disabilities, not just the annual health check



- To develop staff training on reasonable adjustments, with “How to do reasonable adjustments” as a resource for all clinicians
- Explore developing specific pathways for identified areas a constipation pathway  
Consider a dysphagia pathway
- Develop the LeDeR Steering Group work plan to support focused work on specific learning themes, capturing recommendations from reviewers into an action plan for providers.
- Recruiting a sustainable pool of LeDeR reviewers to achieve the NHSE key performance indicators for allocation within 3 months and completion within 6 months of notification.
- Undertake a review to ensure End of Life Pathways are appropriately used and fully involve people with learning disabilities and their families, including the use of accessible information and RESPECT plans.
- Ensure DNACPR is audited to ensure order decisions are appropriately made with safeguarding assessments for mental capacity and best interests assessments fully completed.
- Greater inclusion of people with learning disabilities in our work and their attendance at the steering group workshop events and training programmes.
- Hosting learning events during 2020/21
- Continue to work with system partners, including the West of England Academic Health Science Network Learning Disabilities Collaborative, to share learning and best practice.
- Continue to share learning into actions with the aim of ensuring all people with a learning disability always have good or excellent care

